

Fetal Alcohol Syndrome
and Pregnant Women Who Abuse Alcohol:
An Overview of the Issue and the Federal Response



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EXECUTIVE SUMMARY

Between four and twelve thousand infants with Fetal Alcohol Syndrome (FAS) are born each year. FAS, which results from the chronic heavy consumption of alcohol by women during pregnancy, was identified by researchers in the early 1970s. The syndrome is linked to a number of physical and behavioral abnormalities and is now the leading known preventable cause of mental retardation. The prevalence of FAS in the general population is estimated to be 1-3 cases per 1,000 live births.

When one or more abnormalities in a fetus can be attributed to drinking by the mother, but FAS has not been diagnosed, then the term alcohol related birth defects (ARBD) is used. Both African-American women and Native American women are more likely to be reported to have a child with FAS or ARBD than white women. Although the syndrome has been studied for almost 20 years, researchers cannot yet explain why some women who drink heavily during pregnancy have normal babies.

The human and societal costs of FAS are considerable. The total annual cost of treating the birth defects caused by FAS was estimated at \$1.6 billion in 1985. Eighty percent of that cost, or \$1.3 billion, is accounted for by residential care and support services for mentally retarded persons over age 21 whose impairments are linked to FAS. The cost of neonatal intensive care for growth retardation due to FAS account for \$118 million, while full-time residential care for severely mentally retarded individuals under age 21 accounts for another \$110 million of the total.

Many individuals with FAS do not live with their natural families. One study found that **64%** of FAS children were no longer with the biologic mother by time they were 6 years old, due to removal from the home or the biological mother's death. All children need a stable and nurturing place to call home, but stability and structure are paramount to the functioning of a **child** with FAS or ARBD. While multiple foster care placements are an anathema to an FAS child's basic need for structure, they often occur because the child's needs can overwhelm foster parents. Foster parents who work with these children and other children with special needs may **need** additional training in parenting skills, special support services additional reimbursement to cope with the challenges they face. Adoptive parents may. **also need additional supports.**

Primary, secondary-and tertiary preventive efforts are necessary to reduce the incidence of FAS. Primary prevention focuses on preventing excessive alcohol consumption among pregnant women and preventing pregnancy among alcohol-abusing and alcohol-dependent women. Such efforts include public information campaigns on the dangers of heavy drinking during pregnancy, providing choices of contraceptive methods, and educating children of **alcoholics** about the risks of alcohol abuse. Secondary prevention is defined as intervention

to prevent further deterioration of a person's health. Providing effective and appropriate treatment for alcohol abuse to pregnant women and women of childbearing age is an essential element of a secondary prevention strategy for FAS. Tertiary prevention aims to minimize the long-term disability or mitigate some of its effects. Accurate diagnosis, comprehensive family assessment, and intervention services for the FAS child and other family members are some methods of tertiary prevention for FAS.

There are identifiable gaps in appropriate services, treatment options, data collection systems and knowledge about FAS. While research on various aspects of FAS is ongoing, many basic questions remain unanswered. Examples of some of the questions which research has yet to answer conclusively are:

- What genetic and other physiological factors are responsible for some children being affected by the mother's heavy drinking during pregnancy while others are not?
- What factors place the fetus whose mother drinks heavily-during pregnancy at greater risk of developing FAS or ARBD?
- What role does a father's alcoholism play in the development of a fetus?
- What learning deficits are associated with FAS and ARBD and how are they caused?
- What are successful intervention strategies for working with pregnant women who abuse alcohol, alcohol-abusing women generally, and individuals who have FAS and **ARBD?**

Treatment protocols are needed to help health and social service professionals respond to the changing needs of FAS individuals as they mature. There is also a pressing need for treatment models that address the needs of pregnant women and mothers -for prenatal care, child care and transportation.

More accurate data on FAS and ARBD would provide a clearer picture of the magnitude of the problem and the service **system** that interact with FAS individuals. Among the steps that would improve data collection . . . e: improved surveillance for FAS, more accurate and consistent diagnoses of FAS and ARBD by medical professionals, and a national reporting system for substitute care and child protective services which includes information on **parental substance use**. -Efforts to improve **surveillance and reporting** on **parental substance** abuse are already underway.

The Federal Government has initiated many efforts in the areas of research and surveillance, treatment and services for persons at-risk for or affected by FAS. However, the current prevention, intervention and treatment system is still fragmented and unable to meet the needs of these populations fully. This paper will describe the extent of the problem and some of the current efforts to improve knowledge about FAS and services for persons affected by the syndrome.

UNDERSTANDING FAS AND ITS IMPACT

Alcohol consumption among pregnant women has been the subject of research for 20 years. In 1973, researchers reported a consistent set of abnormal characteristics among infants born to some alcoholic mothers and referred to them as Fetal Alcohol Syndrome.¹ Since that time, research in this area has grown dramatically. In the last decade, the **research** has confirmed that alcohol is a potent teratogen, which is defined as a substance which can cause irreversible damage to the body and brain of the developing fetus. Animal experiments have firmly established the teratogenic effect of alcohol by controlling for other potentially confounding variables such as malnutrition, poor environmental conditions, disease, smoking and the use of other drugs.² FAS is currently the leading known preventable cause of mental retardation.³

This paper will describe FAS and ARBD and review federal efforts in the areas of prevention and treatment of FAS and of alcohol abuse among women. It will discuss the detection, epidemiology, and costs to society of FAS, and describe the FAS child's home environment, the alcohol treatment system and the impact of FAS and parental alcohol abuse on the child welfare system. It will then address prevention strategies, gaps in knowledge about FAS and barriers to services for 'persons affected by FAS. A comprehensive account of the Federal efforts directed at FAS and alcohol abuse during pregnancy is presented in Appendix A.

Identification of FAS and ARBD in Infants

An initial diagnosis of FAS is usually made by a physician or other trained health professional and confirmed by a specialist in dysmorphology or medical genetics. A diagnosis of FAS requires the presence of a certain set of major characteristics in the newborn, and may be confirmed by knowledge of maternal history of drinking. The characteristics are:

- Prenatal and postnatal growth retardation;
- Central nervous system dysfunction (affecting motor as well as cognitive skills);
- At least two of the **following** abnormal **facial features**: **small** head, small **eyes** or short eye openings; a poorly developed **philtrum** (the groove above the upper lip), thin upper lip, short nose, or flattened midfacial area.⁴

It is important to note that FAS is not always apparent at birth. While all newborns with FAS have the facial characteristics noted above, they can be difficult to discern in a **newborn**.⁵ Other physical abnormalities have **been** found to exist in conjunction with the basic FAS characteristics. These may include dental anomalies, lowered immunity to infection, airway obstructions, visual and hearing impairments, speech and language impairments or urinary disorders. They may also include crossed eyes and near-sightedness, malformed ears, heart murmurs, liver and kidney problems, retarded bone growth and skeletal defects, increases in upper respiratory infections and in middle ear infections, undescended testicles and **hernias**.⁶

ARBD is characterized by one or more abnormalities that can be attributed to prenatal alcohol exposure, including partial manifestations of **FAS**.⁷ Typical effects include low birthweight, subtle behavioral problems, or a partial display of physical malformations.* There is some evidence that the partial manifestations of FAS-seen in **ARBD** individuals are associated with variations in dose, timing, conditions of prenatal alcohol exposure and genetic differences among **individuals**.⁹

Characteristics of FAS Children

Some of the more commonly observed characteristics of infants and young children with FAS are increased irritability, gross motor and fine motor delays, weak sucking and disrupted sleep patterns, hyperactivity and absence of stranger **anxiety**.¹⁰ It is common for children with FAS to have problems with learning, attention, memory and problem solving, along with lack of coordination, impulsiveness and speech and hearing impairment.” In addition, children and adults with FAS may not function at a level consistent with their **IQ**.¹² While many children with FAS have **IQs** in the normal range, others suffer from mental retardation¹³ In fact, FAS is now considered the leading known preventable cause of mental retardation.¹⁴

A number of characteristics are associated with FAS in adolescence and adulthood. Adolescents or adults with FAS often exhibit deficits in learning skills that have persisted **from** early childhood.¹⁵ Shorter stature, slightly lower than normal weight mass and smaller head circumference are common characteristics, as are dental anomalies, skeletal and postural anomalies and abnormal facial features. Behavioral indicators of FAS in adolescence that continue in adulthood include impulsiveness, lack of inhibitions, poor **judgment, and a lack of understanding of socially appropriate sexual behavior**.¹⁶ These behavioral characteristics make it difficult for FAS individuals to find and maintain work as well as establish a peer group.”

Causes of FAS and ARBD

FAS and ARBD both result from the consumption of alcohol by a pregnant woman. When a pregnant woman drinks, the alcohol enters the fetus' circulatory system through the placenta. This results in fetal blood-alcohol levels that equal blood alcohol levels in the mother.¹⁸ The amount of damage produced by prenatal alcohol exposure depends on the fetus' stage of development, genetic factors, environmental variables, and the frequency and quantity of the mother's alcohol consumption. The exact mechanisms by which alcohol exerts its effect on different organ systems have not yet been confirmed.

The relationship of alcohol consumption by biological fathers to FAS and ARBD is not fully understood. Long-term consumption of large quantities of alcohol by men has been associated with impotence, reduced sperm motility, loss of sperm and abnormalities in sperm structure.¹⁹ Fertilization with a defective sperm may result in fetal anomalies, but no direct relationship to alcohol consumption has been established. Several animal studies suggest that the male parent could contribute to alcohol-related birth defects. However, there is not currently enough evidence to support the conclusion that a direct relationship of this sort exists among humans.

Detection of FAS

Unfortunately, many children with FAS are detected by health professionals only after they fail to gain weight and meet developmental landmarks. Some are not identified until they begin having difficulty in school or display abnormal behaviors. Others are never **recognized**.²⁰

Accurate detection is a necessary precursor to providing appropriate services to the alcoholic mother and FAS child. As with other disabilities, early identification increases the opportunities for interventions that may mitigate the severity of the syndrome and provide assistance to the affected person's family. Ideally, a multidisciplinary professional team should conduct the diagnosis and evaluation and link the FAS individual with the necessary developmental, emotional/behavioral, educational, special medical testing, visual screening, and hearing services.

Good **detection** and surveillance will also provide incidence data that will allow policymakers to measure changes in the number of affected individuals and their need for services and enable FAS prevention programs to target high-risk groups. Legislation enacted in 1989 requires State health departments to begin annual reporting on the incidence of FAS as a part of their responsibilities under the Maternal and Child Health Block **Grant**. Improved reporting procedures may reveal a higher incidence of FAS than is now **estimated**.²¹

Failure to diagnose FAS may be a function of a physician's failure to recognize alcohol abuse or alcoholism in the parents, inability to provide treatment or follow-up for the full range of FAS symptoms, concerns about 'labeling' children, lack of available services, or lack of training in the diagnosis of this syndrome.** A survey of pediatricians reported that many doctors lack appropriate mechanisms for diagnosing and treating FAS, such as a **registry** of services appropriate for FAS and ARBD children, sufficient training for themselves and a pregnancy/alcohol history checklist for use with patients. They also lack literature on FAS and ARBD for parents and future parents.²³ Unfortunately, physicians' underreporting of FAS has resulted in inaccurate incidence and prevalence data."

Detection of Alcoholic Mothers

Accurate identification of a pregnant woman's alcohol abuse is a prerequisite for intervention and prevention of FAS and other alcohol related birth defects. Women who abuse alcohol can be identified at any point in the pregnancy or at the time of delivery; **which** for many low-income women is the first point of contact with the health care system. Questions about alcohol ingestion during pregnancy can be asked as part of the routine medical history, but cannot always be verified by blood or urine toxicology tests. In fact, the blood tests of known alcohol users are frequently negative due to the rapid elimination rate of alcohol from the **body**.²⁵

As with the identification of drug abuse, the identification of alcohol abuse appears linked to physicians' perception of their female patients as belonging to a high risk group. Some experts believe that women of lower **socio-economic** status are correctly diagnosed as alcoholics more often than women of higher economic **status**.²⁶ This may be a factor in the apparent higher incidence of FAS and ARBD among Native Americans and **African-**Americans than among whites.

Self-reporting, or the use of standardized questionnaires, is often used to obtain information on alcohol use. One such instrument, called T-ACE, is a **brief** questionnaire designed to help circumvent denial and underreporting of heavy drinking by pregnant women. In a 1989 study, the T-ACE questionnaire correctly identified 69% of the "risk-level" drinkers in the **sample**.²⁷ Research on self-reporting is not as encouraging. One study revealed significant underreporting of alcohol use during pregnancy.²⁸ The study compared the reported alcohol use during pregnancy when the women were pregnant and five years later and found that the responses given at the **later point in** time **indicated a** higher level of alcohol use than the responses **given** while the women were pregnant. These results reflect the tendency to deny engaging in risky behavior.

Epidemiology

Alcohol Use

It is clear that all FAS children were exposed to heavy maternal **drinking**.²⁹ However, the fact that many women who **drink** heavily during pregnancy have apparently normal babies has not been fully explained.³⁰ Researchers have been unable to identify a threshold amount of alcohol consumption that can be linked to FAS, or to identify a predictable dose-response relationship. Some animal research relates specific developmental anomalies in FAS to the frequency and trimester in which alcohol was **consumed**.³¹ Animal research has also indicated variable susceptibility of fetuses to alcohol's adverse effects despite similar levels of exposure."

There is a dearth of information on the number of women of childbearing age or pregnant women who abuse alcohol. However, it is known that of the 15.1 million alcohol-abusing or alcohol-dependent individuals in the United **States**, **approximately** 4.6 million (one-third) are women.³³ Women ages 18-34 report higher rates of problems related to drinking than do older **women**.³⁴ However, the incidence of alcohol dependence is greater among women ages 35-49 than among women in the 18-34 age group."

Researchers have identified other demographic subgroups that have relatively high rates of **alcohol** abuse. Women who are divorced or separated, who have never married or are unmarried but live with a partner, are at greatest risk. Other high risk groups include women who are unemployed and looking for work, women who are employed part-time, women in their twenties and early thirties and women with heavy-drinking husbands or partners.% While there is a national trend towards lower per capita consumption of alcohol, there is an increase of heavy drinking among young adults, both male and female." Young adults will continue to be a high risk population of great concern.

Although estimates vary, it has been established that there are more alcohol abusers than abusers of other drugs. The number of Americans who suffer from alcohol abuse or alcohol dependence is more than five times the most recent estimate of regular cocaine or crack **users**.³⁸ Moreover, researchers and drug treatment providers have found that many of the women who are using drugs during pregnancy are also using alcohol."

Overall Incidence of FAS

The reported incidence of FAS varies widely and depends on the location of the study and the population under study. It also depends on the quality of the reports; many experts believe that physicians diagnose and report FAS selectively, depending on their awareness of the disorder and on the patient's race or ethnic group. Some research indicates that between 4,000 and 12,000 children are born each year with FAS, which translates to an estimated incidence rate for the general U.S. population of 1-3 per 1,000 live **births**.⁴⁰ Estimates of the incidence of ARBD are less precise than those for FAS. One study suggested that the incidence of **ARBD** may be two to three times that of **FAS**.⁴¹

While selective diagnosis and reporting may skew the results, existing research indicates that the characteristics of the study population can have a significant effect on the calculated incidence of FAS. For example, a review of several different studies of heavy drinking and/or alcohol dependent women reported an aggregate incidence rate of **.25** per 1,000 live births per year.⁴² Most identified cases of FAS come from study sites where the mothers were African-American or Native American women of low socioeconomic status. The estimated incidence rates at these sites were as high as 2.6 per 1,000, as compared with **.6** per 1,000 for studies conducted at sites where women were white and of higher socioeconomic **status**.⁴³ One study, which compared the children of high-income white chronic alcoholic women to children of lower-income African-American and Hispanic chronic alcoholic women, found that 40.5% of the children of lower-income mothers and 3 % of the children of higher-income mothers had **FAS**.⁴⁴

Incidence Among Different Groups

Several studies have reported a significant difference in FAS incidence rates among various ethnic populations. Hispanics and whites have a lower rate than African-Americans and some Native American and Alaskan Native groups." The variation between ethnic groups may be more related to **socio-economic** risk factors -- such as poor nutrition, smoking and unemployment -- than **ethnicity**.⁴⁶

Hispanics have the lowest reported FAS incidence rate of all ethnic groups." A 1984 study found that more than 70 percent of Hispanic women drank either less than once a month or not **at all**. The same study found that **Mexican-American** women had a much higher rate of **both** abstinence and heavier drinking than women of Puerto Rican or Cuban **origin**.⁴⁸ Despite the overall low incidence rates of FAS among Hispanics, the projected growth of the Hispanic population into the Year 2000 means that Hispanics should not be excluded from discussions of detection and prevention of **FAS**.⁴⁹

FAS is a serious problem for some Native American communities. The most reliable study of incidence among Native Americans in the Southwest was conducted in 1983. This study reported an overall incidence rate of 6.1 per 1,000 live births, ranging from 1.3 per 1,000 live births (1 in 749 births) to 10.3 per 1,000 (1 in 97 births) among different Native American groups.⁵⁰ In this study, 25% of all the Native American mothers who had given birth to one fetal alcohol-affected child had also given birth to others.

The Indian Health Service (IHS) reports different incidence rate for Native American communities in other parts of the U.S. The incidence of FAS across the state of Alaska during the 1981 to 1986 period was reported at 4.2 per 1,000 live births, with a range in various regions of 1.4 to 12.2 per 1,000 live births. Since an FAS prevention program was established by the Alaska IHS in 1986, continued surveillance showed an incidence rate from June 1986 to December 1988 of 2.7 per 1,000 live births.⁵¹ In addition, the IHS reported a drop in incidence rates of FAS in its Billings region (covering Montana and Wyoming) from 18.2 per 1,000 live births in 1979 to 5.3 per 1,000 in 1985.⁵²

Native Americans are not the only minority group seriously affected by **FAS**. **African-American** women are seven times more likely to have FAS **children** than white women with similar drinking habits.⁵³ Factors associated with heavy drinking are also associated with poverty (cigarette smoking, poor nutrition, and drug use) and may work in combination with alcohol consumption to increase the risk for FAS and ARBD among **African-Americans**.⁵⁴

IMPLICATIONS FOR CURRENT SYSTEMS

The Cost of FAS

The costs of alcoholism are significant to society at large as well as to individuals. The economic costs are typically measured in terms of the direct cost of diagnosis and treatment, the indirect costs of lost or reduced productivity (loss of earnings), premature death, and other related costs. According to the most recent estimate, the total economic cost of alcohol abuse was \$70.3 billion in 1985.⁵⁵

The costs associated with FAS are also extremely high. The total annual cost of treating the birth defects caused by FAS was estimated at \$1.6 billion in 1985.⁵⁶ Eighty percent of that cost, or \$1.3 billion, was accounted for by residential care and support services for mentally retarded persons over age 21 whose impairments are linked to FAS. **The cost** of neonatal intensive care for growth retardation due to FAS made up 7% of the total (\$118 million) in 1985, while full-time residential care for severely mentally retarded individuals under age 21 accounted for another 7% (\$110 million).⁵⁷ According to the Alaska Office of Alcoholism and Drug Abuse, a lifetime of care for an FAS individual can cost \$1.4 million.⁵⁸

There are a number of costs associated with FAS and ARBD that cannot be quantified, and some of these are associated with under-reporting. Among these are the psychological costs to the children and emotional costs to parents and other caregivers. Productivity losses due to FAS are generally unmeasured, except after death.⁵⁹

Alcohol Treatment System

There is very little information available on the number of women in their childbearing years who seek treatment for alcoholism and what proportion of those in need receive it. According to the National Drug and Alcoholism Treatment Unit Survey (NDATUS), women made up 25% of all clients for alcoholism treatment in 1989.⁶⁰ In certain states, however, women made up one-third or more of clients in treatment for alcoholism.⁶¹ Based on information from NDATUS on the age of all alcoholism clients and the proportion of all clients who are women, it appears that approximately 50,000 female alcoholism treatment clients are between the ages 25 and 44.⁶²

The NIDA and NDATUS data do not provide information on the number of women who receive treatment for alcohol abuse that is tailored to their special needs as women and mothers. Anecdotal reports indicate that many women who abuse alcohol have trouble finding such programs. For example, very few treatment programs provide child care and many use a therapeutic model that was designed for alcoholic men. *(For further discussion of appropriate treatment, see Secondary Prevention).*

Home Environment

An unhealthy home environment can adversely affect any child's developmental progress. The depression, stress and other psychological problems associated with adult alcoholism can lead to depression, low self-esteem and learning disabilities in **children**.⁶³ These problems have been observed in children who do not suffer from FAS as well as in those who do, and **can** put children at increased risk of child abuse and neglect. Children of alcoholic parents are also at risk of developing alcoholism when they **become adults**.⁶⁴

An FAS or ARBD child's home is often characterized by few economic resources and little emotional support.⁶⁵ If an FAS child has been removed from the home because of concerns about child abuse or neglect, child welfare workers must conduct a comprehensive assessment of the home environment before returning the child to ensure safety, supervision and provision of adequate nourishment. Educating alcohol-abusing parents about the effects of their drinking on the family, teaching them about FAS and ARBD and demonstrating parenting skills may help them cope with their children's behavior and provide the children with appropriate role models. However, caring for FAS children is extremely difficult even for non-alcoholic parents.

Child Abuse and Out of Home Care

While educating parents is important, it does not help the many individuals with FAS who do not live with their natural families. A study of FAS individuals between the ages of 12 and 40 revealed that 23% lived with their natural families, 26% -in foster homes, 21% with relatives, 16% in adoptive homes, 5% in group homes, 4% in institutions and 5% lived alone but with some type of financial or social support.⁶⁶ Although the FAS individual is generally not capable of self-sufficiency, proportionally few families remain actively involved with a person affected by FAS. In the same study, 64 % of FAS children were no longer with the biologic mother by time they were 6 years **old**.⁶⁷ This reflects removal from the home or the biological mother's death. The mother of an FAS **child** often dies young for reasons related to alcohol **abuse**.⁶⁸

Many FAS children come into contact with the child welfare system, which provides services for neglected, abused, exploited or delinquent children. These services can include investigation of suspected abuse and neglect, supportive services for troubled families, removal of children **from** their homes if necessary for their protection, attempts to reunite children with their natural families, financial support to maintain children living in out-of-home care, and services to place children for adoption or in other permanent living arrangements if family reunification is not feasible. @ In some areas, foster parents **who care** for children with special medical needs or disabilities receive funds to supplement the standard level of reimbursement.

There is limited data on the number of children that enter the substitute care system, and even less information on how many children enter the system as a result of their parents' alcohol abuse. Data on parental behavior precipitating an allegation of abuse or neglect is not consistently collected by states. Many states are now revising their data collection systems to include additional information on substance abuse by family **members**.⁷⁰ In addition, the Department of Health and Human Services is developing reporting systems for state substitute care and child protective services agencies that should include this **information**.⁷¹

While all children need a stable and nurturing place to call home, stability and structure are paramount to the functioning of a child with FAS or ARBD. Providing for the best interests of these children presents a challenge to the substitute care system. While multiple foster care placements are an anathema to an FAS child's basic need for structure, they often occur because the child's needs can overwhelm foster parents. Foster parents who work with these children and other children with special needs may need additional training in parenting skills, special support services and additional reimbursement to cope with the challenges they **face**.⁷² Adoptive parents may also need additional supports.

PREVENTION AND INTERVENTION STRATEGIES

Intervention for the population at risk of FAS must begin with preventive services. Prevention includes primary, secondary and tertiary efforts. Research, education, treatment and other preventive services are provided at all levels of government as well as by non-profit and for-profit organizations. The Federal Government has numerous programs addressing each of these areas. The departments involved in such efforts include Department of Health and Human Services, Department of Education, Department of Agriculture, and Department of Interior. These agencies' programs are described in Appendix A.

Primary Prevention

Primary prevention attempts to prevent the occurrence of a health problem. The Department of Health and Human Service included a number of primary prevention goals in "Healthy People 2000," a 1990 report that sets forth national health objectives for the next decade. The primary prevention efforts that pertain to FAS are achieving abstinence from alcohol by pregnant women and increasing the choice of contraceptive methods.

One aspect of primary prevention of FAS concerns preventing additional alcohol-exposed pregnancies. Women who have had one FAS child are at serious risk of having another if they continue to drink heavily.⁷³ Intervention to stop or reduce alcohol consumption during pregnancy can not only reduce the risk to the fetus, but also prevent damage to future children. Expanding the choice of contraceptives for women could decrease the incidence of FAS by decreasing the number of pregnancies among women who drink." However, women's alcoholism, and the possibility that some alcohol dependent women may have FAS or ARBD themselves, is likely to interfere with education about and the practice of **contraception.**⁷⁵

Another form of primary prevention for FAS involves public information campaigns. One of the Federal Government's efforts to inform the public about the dangers of alcohol is the implementation of the federal warning label law. The label, which has been required on all wine, beer, liquor and wine coolers since 1989, states the health risks associated with consuming the beverage, including risks during **pregnancy.**⁷⁶ "Healthy People 2000" suggests that counseling by health care providers before a woman becomes pregnant can reinforce **the public awareness messages now required on alcoholic beverages.**"

Media campaigns have also been sponsored by public health advocacy groups to encourage a reduction in alcohol consumption. Such efforts have several goals: delaying the onset of drinking, reducing minors' access to alcohol, creating alternatives to drinking, providing information about the effects of alcohol consumption, encouraging enactment of stricter drunk driving laws, creating greater awareness of the laws and increasing abstinence from alcohol consumption during **pregnancy.**⁷⁸

Public information campaigns do raise the level of awareness about alcohol abuse, but there is no evidence that this information reduces the number of women who drink **heavily**.⁷⁹ In fact, women who are at greatest risk of having children with alcohol-related birth defects are the least responsive to broad information campaigns.” The most important reason for this is the nature of addiction, which prevents alcohol dependent women from discontinuing their drinking despite their knowledge of the negative **consequences**.⁸¹

Within the Department of Health and Human Services, the primary responsibility for public education to prevent alcohol abuse rests with the Office for Substance Abuse Prevention (OSAP). In addition to media campaigns, OSAP awards grants for the establishment of model projects for prevention, education and treatment for alcohol and drug abuse for pregnant and post-partum women and their infants. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has statutory responsibility for research on the causes, prevention, treatment and consequences of alcohol problems and for the dissemination of research findings. Other Federal agencies, such as the Department of Education and the Department of Transportation, are also heavily involved in public education about alcohol abuse. (See *Appendix A*)

Some experts believe that the prevention of alcohol abuse could be greatly enhanced if more attention was directed to the high-risk population of children of alcoholics (COA). Because of genetic and environmental factors, these children are at higher risk of abusing alcohol than other **children**.⁸² In fact, COA are 2-4 times more at risk for alcoholism and other substance abuse than children of non-alcoholics. It is estimated that there are 26.8 million COA in the United States, 6.6 million of whom are under the age of **18**.⁸³ Most school-based programs on substance abuse discuss the dangers of drugs and alcohol but do not directly address the issue of COA.”

Secondary Prevention

Secondary prevention consists of attempts at early identification and treatment to prevent further deterioration of a person’s health. Such efforts could significantly reduce the risk of alcohol consumption during pregnancy to a woman and her unborn child. At a minimum, physicians and other medical personnel who treat pregnant women should be aware of alcohol abuse resources in the community so they can make referrals to the appropriate services.

~~There are several approaches to treatment~~ for alcohol -abuse., ~~The most common~~ are individual and group therapy, family and marital therapy, and social skills training. Individual and group psychotherapy are typically used in conjunction with education about alcohol dependence, referral to Alcoholics Anonymous (AA), family therapy, pharmacologic therapy, and vocational **rehabilitation**.⁸⁵ Psychotherapy and counseling are the fundamental components of most alcoholism treatment programs.

Alcoholics Anonymous, and its related programs for family members of alcoholics, is an essential element of many therapeutic programs. In 1987, there were over 73,000 AA groups throughout the world and 34% of AA members were women. AA's effectiveness has not been scientifically documented. One study found that AA's highly structured program is most effective for those alcoholics who have lost control over their drinking and believe they are powerless.⁸⁶ Others note that an integral aspect of AA is the acceptance of responsibility for one's own behavior as a path to **recovery**.⁸⁷ The average length of sobriety for AA members surveyed in 1987 was 52 **months**.⁸⁸

Many alcohol abusing women do not receive treatment that is tailored to their specific needs and some do not receive any treatment at all. Among the obstacles to treatment are a woman's lack of health insurance, child care and transportation to reach the treatment **site**.⁸⁹ In fact, lack of child care is one of the most frequently reported barriers to treatment for alcoholic **women**.⁹⁰ Other factors are the lack of treatment facilities and the lack of quality treatment approaches that are sensitive to women's particular needs as a woman and mother.⁹¹ Additional obstacles are treatment facilities' inability to monitor high-risk pregnancies, lack of **support** from friends or family, lack of job **counseling**, negative expectations, and the denial and social stigma associated with alcohol **abuse**.⁹²

Traditional treatment models are based on the assumption that the person has to "bottom out" in order for treatment to be effective **and** often rely on confrontational **approaches**.⁹³ Such approaches are not the best methods of addressing the issues that plague women who drink. Among these are low self-esteem, depression, and histories of sexual abuse that include incest and **rape**.⁹⁴ Treatment professionals observe that a supportive, non-confrontational environment is essential for an alcohol-abusing woman to confront her problem."

Supportive treatment needs to focus on the emotional needs and the role expectation of alcoholic women, and to provide follow-up services during the transition **from** treatment to a lifestyle free of substance abuse. Since many women report drinking because they are in the company of other family members who **drink**,⁹⁶ treatment providers should involve all members of the family in the rehabilitation process.

Treatment that involves supportive therapy is a critical part of the prevention strategy. Some research indicates that women who receive supportive treatment and consequently reduce their heavy drinking before the third trimester of pregnancy deliver babies that are less damaged than women who drink heavily throughout their pregnancy." While it may not be possible to persuade heavy drinkers to do more than moderate their drinking habits, light to **moderate drinkers may** achieve **abstinence through treatment or spontaneously** reducing alcohol consumption during pregnancy.

Another aspect of effective substance abuse treatment is sensitivity to cultural differences between and within ethnic groups. For example, providers who serve Native American populations must be aware of the differences between Native American and American culture and the wide variation in cultures and patterns of alcohol and drug use among the over **300** existing Native American tribes.⁹⁸ In order for treatment providers to be successful, they must be aware of the unique treatment needs of their local community.

Tertiary Prevention

Tertiary prevention aims to minimize long-term disability or reduce negative effects. In the context of FAS, such efforts could include: consistent and accurate diagnosis and reporting, providing interventions for the infant born with FAS or ARBD, services for the individual with FAS or ARBD throughout development and into adulthood and for the alcohol-abusing parent, and consistent follow-up services for the FAS-affected individual and the alcohol-abusing woman.

Infants born with FAS and ARBD need evaluations and assessments. Using funds from Part H of the Individuals with Disabilities Education Act (**P.L. 99-457**), states are beginning to provide early intervention services to infants and toddlers (age 0-2) who are developmentally delayed. States have the option of covering infants and toddlers who are at risk of developmental delays. (See **Appendix A, Department of Education**) While the early intervention program may provide the necessary medical, motor, language or behavioral interventions for children aged **0** to **2**, there are few programs that provide a truly comprehensive range of interventions for FAS children. A complete intervention program would establish an individualized treatment plan with periodic reviews followed by special education for school age children. The treatment plan would focus on developing the child's functional skills and exploring the child's strengths.⁹⁹ Such a plan would also include vocational training for the adolescent or adult affected by FAS.

An important component of tertiary care is follow-up for both the child and the mother. If an assessment or service is recommended for the child, follow-up is needed to ensure that it is received. If the mother continues to drink after the birth of the child, then follow-up with substance abuse treatment needs to be a part of the intervention plan.

Finally, at-risk families need to receive information and appropriate financial, social and clinical services from the moment the mother's alcohol abuse is detected. The parent(s) may need counseling services, job services, food and shelter assistance, or parent training. Provision of such services from the beginning may help to lessen the risk of ill effects on children living with alcohol abusing parents.

GAPS IN KNOWLEDGE AND SERVICES

While FAS has been studied for almost 20 years, there are still a number of gaps in knowledge and barriers to identifying and serving the FAS-affected population. The problems are concentrated in the areas of research, detection and diagnosis, services for FAS adults, treatment, benefits, and data collection.

Research

Despite 20 years of research, researchers and policymakers are still grappling with many questions about the syndrome. Among the unanswered questions are the following:

- Why are some children affected by their mother's drinking while others are apparently not?
- Why are some children born with FAS and others born with ARBD?
- What level of alcohol exposure is required to produce a child with FAS? Or with ARBD?
- When are the critical times in pregnancy when alcohol ingestion will most affect the fetus?
- What factors place the fetus at a greater risk of developing FAS or ARBD?
- What role does a father's alcohol consumption play in the development of the fetus?
- What learning deficits are associated with in utero exposure to alcohol generally, and with FAS and ARBD in particular? How are these learning deficits caused?
- What are successful intervention strategies for working with pregnant women who abuse alcohol, alcohol-abusing women generally, and individuals who have FAS or ARBD?
- How effective have states been in using the Alcohol, Drug Abuse and Mental Health Services (ADAMS) block grant's women's set-aside to fund alcohol-abuse treatment programs?

Detection and Diagnosis

Some health professionals are aware of the symptoms and signs of FAS and ARBD but are unable to diagnose it in a newborn or infant, while others may diagnose it selectively according to the patient's socioeconomic status, race or ethnicity. There are still others who are not familiar with the syndrome. It is important to educate health care professionals about FAS and **ARBD** in formal academic settings and through continuing professional education. It may also be useful to develop objective methods of diagnosis - such as a set of standard craniofacial measurements that indicate FAS -- so that physicians who are not specialists in the area can more easily identify the syndrome.

In addition to improving health professionals' ability to diagnose and willingness to report FAS and ARBD, improvements need to be made in surveillance of the syndrome. Experts suggest that there should be more emphasis on active surveillance, meaning examination of hospital charts and medical records to identify babies with FAS, instead of **waiting** for physicians or other health professionals to identify the problem. The Centers for Disease Control has recently initiated two projects to improve surveillance for FAS that are more fully described in Appendix A.

Treatment for Alcohol Abuse

Appropriate and accessible treatment is an issue for the alcohol-abusing pregnant woman, the alcohol-abusing woman generally, and for individuals directly affected by FAS. The two most pressing problems that concern treatment for alcohol-abusing women are the limited supply of treatment facilities for women **with** children and pregnant women's limited access to treatment services. Among the obstacles to treatment for women include the lack of health insurance, inadequate child care, and the lack of transportation to treatment facilities. In addition, access to treatment is hampered by the limited number of programs that are sensitive to women's unique concerns, treatment facilities' inability to monitor high risk pregnancies and a woman's lack of support from friends and family.

In addition to providing more treatment facilities that are appropriate for pregnant women and women with children, more needs to be done to bring current and potential alcohol abusers into treatment. Improvements are needed in outreach to pregnant women who are **already using alcohol** or drugs and to children of alcoholics to prevent **alcoholism** from occurring among this -high risk group. On the other end of the treatment spectrum, there is a need for follow-up services to assist women in recovery from returning to the abuse of alcohol. These services will be most effective if they involve the woman's family in the recovery process.

Appropriate Services

While children age 0-2 are eligible to receive early intervention services through the P.L. 99-457 legislation and older children may be eligible for special education services, a number of children with FAS or ARBD may not be served by either of these mechanisms. Children who are not diagnosed with FAS or ARBD, who have **ARBD** but are not considered developmentally delayed, or who live in states that have not opted to cover infants and toddlers at risk of developmental delays may not receive the interventions they need. This problem grows more acute as individuals with FAS age and may no longer be eligible to receive educationally-based services because they drop out of school.

Improvements in detection and diagnosis and in the education of health professionals about FAS should assist with identifying children who are developmentally delayed or at risk of delays because of FAS and ARBD, which may improve their chances of receiving services through the early intervention and special education systems. Some individuals with FAS may be able to receive services through the mental retardation/developmental disabilities service system. However, health and social service professionals and state legislators need to be made aware of the unique characteristics of FAS children -- including the fact that some FAS children have **IQs** in the normal range -- that may disqualify them for existing services.

Unfortunately, **the** behavioral characteristics of many adults with FAS are not conducive to independent and productive futures. Because of their impulsiveness, inappropriate sexual behaviors, inability to identify danger and excessive friendliness, adults with FAS may be taken advantage of, abused or become involved in deviant behavior. These are known behavior patterns and yet there are very few treatment or therapeutic options for adults with FAS and ARBD. As a result, they are likely to be served by one or more of the following systems: adult protective services, subsidized or shelter housing, drug or alcohol rehabilitation, rape crisis or criminal justice. The needs of individuals with FAS and ARBD evolve from childhood to adulthood, and therapeutic models should provide a continuum of services that respond to these changing needs.

Benefits

Some families have found it difficult to obtain **benefits**, particularly Supplemental Security Income (SSI), for individuals with FAS or ARBD. SSI provides cash benefits to needy 'elderly, blind, and disabled individuals and couples who live in families, foster care or institutions. Individuals with FAS have had trouble qualifying for SSI for **two reasons**: many FAS children **are developmentally** disabled but have **IQs** that are too high to allow them to qualify for benefits, and FAS is not included in the medical listings used to determine eligibility for disability benefits.

Recent changes to the SSI regulations will make it easier for some children disabled by FAS to qualify for benefits. One is an update to the list of medical impairments that includes the multiple system/body damage often associated with disorders such as FAS. Another is a new requirement that the Social Security Administration perform an individualized functional assessment for each affected child whose impairments do not meet or equal the severity of impairments included on the SSI medical listing. Both of these changes will enable more children with FAS to receive SSI. Since eligibility for SSI also establishes eligibility for Medicaid in thirty-nine states, these changes will also help more individuals with FAS obtain health insurance. (See *Appendix A*)

Data Collection

The improvement of data collection in the health care and child welfare systems will enhance our understanding of FAS and facilitate the provision of necessary services. In the public health arena, more aggressive surveillance for FAS and ARBD will provide better information on incidence in different communities. As noted earlier, developing more objective methods for diagnosing FAS and educating medical professionals about the syndrome should lead to improved rates of diagnosis among non-specialists and to more evenhanded reporting of FAS among different racial and ethnic groups. When information about incidence rates is more **accurate**, **resources** can be more productively directed toward prevention and intervention activities.

In the child welfare area, state substitute care and child protection agencies are just beginning to collect information on parental substance abuse on a routine basis. The Department of Health and Human Services is establishing a mandatory reporting system for substitute care agencies and a voluntary reporting system for child protective services agencies. The information gathered through these new reporting systems should improve prevention and intervention efforts for the child and family affected by alcohol abuse.

CONCLUSION

Over the last twenty years, research has generated new information and practitioners have gained new insights into the diagnosis, treatment and prevention of FAS and ARBD. Much has also been learned **about** the development of children who suffer from FAS and their need for specialized services. Despite these efforts, current knowledge about FAS is limited, the existing service system is fragmented and too many of the population at-risk for alcohol abuse and FAS do not receive the services or benefits they need.

This paper has described the special problems and needs of children with FAS and the impact of FAS and **ARBD** on the health and social service systems. It has also outlined prevention and intervention strategies and gaps in knowledge, detection and diagnosis, treatment, other services, benefits and data collection. Finally, this paper has discussed ongoing Federal efforts to improve the quality of knowledge about FAS, ARBD and alcohol abuse and services for children and families affected by them.

The Federal Government has initiated a number of programs in the areas of FAS research, surveillance, data collection, appropriate services and benefits and the prevention and treatment of alcohol abuse. Much more-remains to be done. As long as alcohol remains freely available and socially acceptable, the risk of FAS will be with us. This fact, and the fact that FAS is a completely preventable problem, is a powerful call to action.

APPENDIX A

FEDERAL EFFORTS CONCERNING FETAL ALCOHOL SYNDROME

A number of Federal agencies are engaged in research projects, prevention efforts, service delivery systems, and education campaigns that address FAS or ARBD directly or indirectly by addressing maternal and child health, substance abuse and income support issues. The following is a list of Federal programs that can and do serve alcohol abusing pregnant women and individuals with FAS and ARBD. This listing will be updated periodically to provide the most current information on programs.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

Assistant Secretary for Planning and Evaluation (ASPE)

The Secretary has identified nine major priority areas that are referred to as “Program Directions”. ASPE is the designated office responsible for the coordination and tracking of these program directions. Of these nine areas, four are related to the needs of the alcoholic woman and one specifically addresses alcohol abuse among women of child bearing age. The relevant program directions are as follows:

Program Direction #3: Reduce the incidence of smoking and alcohol problems among children, youth, young adults and women of child bearing age.

Objective: Launch a major and highly visible **HHS** initiative to reduce alcohol abuse. (Agencies responsible include: the Public Health Service with the Health Care Financing Administration, the Social Security Administration, the Administration on Children and Families, in coordination with the Departments of Transportation and Treasury).

Subobjectives:

- Conduct target interventions **to reduce** alcohol problems among the general population, with an initial focus on alcohol-impaired driving;
- Reduce alcohol abuse by Native Americans and Alaska Natives;
- Reduce alcohol abuse among high-risk youth;
- Reduce alcohol abuse among pregnant and **post-partum** women.

Program Direction **#5**: Improve access of youth living in low-income families to needed support services, including employment training, other transition to work services, and adolescent pregnancy related services. (Agencies responsible include: the Social Security Administration, the Public Health Service, the Administration on Children and Families, the Office for Civil Rights, and the Office of the Assistant Secretary for Planning and Evaluation).

Program Direction **#6**: Improve the integration, coordination and continuity of the various I-IHS-funded services potentially available to families currently living in poverty.

Objective: Improve the coordination and integration of health services for all **low**-income families, and identify opportunities for integrating other programs. (Agencies responsible include: the Public Health Service, the Health Care Financing Administration, the Administration on Children and Families, and the Office of the Secretary, and in coordination with the Departments of Agriculture and Interior).

Program Direction **#8**: Improve access of young children and their families living in poverty to a wide array of developmental, support services, and income assistance, including nutrition, foster care, health, mental health, social and child protective services. (Agencies responsible include: the Health Care Financing Administration, the Public Health Service, the Office of the Inspector General, the Administration on Children and Families, the Social Security Administration, the Office of the Assistant Secretary for Planning and Evaluation, and the Office of the Secretary).

Inspector General

Sen. John **McCain** (R-AZ) has asked the Inspector General's office to evaluate the Federal Government's alcoholism prevention and education efforts for Native Americans. This is in preparation for reauthorization of the Indian alcohol and drug prevention and treatment programs next year.

Public Health Service

Office of the Assistant Secretary for Health (OASH), Office of Women's Health.

This newly created office will conduct oversight of the Public Health Service action plans on women's health issues.

Alcohol, Drug Abuse and Mental Health Administration (ADAMHA)

On June 17, 1991, the Secretary of HHS proposed a reorganization of **ADAMHA** that would move its three research institutes -- **NIAAA**, **NIMH** and **NIDA** -- to the National Institutes of Health. **ADAMHA** would retain the Office for Substance Abuse Prevention (OSAP) and the Office for Treatment Improvement (OTI) and house a new Office for Mental Health Services. The proposed reorganization has not yet gone into effect.

The Alcohol, Drug and Mental Health Services (ADMS) Block Grant. The ADMS grant provides funds to the States who then determine how the money will be used. The mandated set-aside for women's alcohol and drug abuse services is 10% with an emphasis on programs for pregnant women and women with dependent children.' The total block Grant funds available for FY 91 are \$1.268 billion; the set-aside for women is \$126.8 million.

Health Professions Education Program. (See *NIAAA*)

National Drug and Alcoholism Treatment Unit Survey (NDATUS). This survey collects data from alcohol and drug abuse treatment programs on client demographic profiles, number of clients, and treatment capacity. In 1990, questions will be added on the treatment of pregnant addicts.

¹ **The** ADMS Block Grant was established in 1981 as part of the Omnibus Budget Reconciliation Act of 1981. In 1984, Congress reauthorized the block grant and included a set-aside for women's alcohol and drug abuse services. There is currently one legislative proposal to increase the set-aside from 10% to 15%.

The Office for Treatment Improvement (OTI). OTI was established to address drug abuse treatment issues. Two of OTI's demonstration programs are relevant to pregnant and postpartum women who abuse drugs alone or in combination with alcohol:

(1) Critical Populations Demonstration Grant Program

This program funds comprehensive drug treatment for racial and ethnic minorities, residents of public housing projects and **adolescents**. In FY 1990, the first year of the program, \$24.2 million was awarded to 80 projects throughout the U.S.

(2) Target Cities Demonstration Grant Program

This program is designed to establish comprehensive and coordinated drug treatment in cities with a population of at least 315,000. Thus far, \$28 million has been awarded to eight cities.

The Office of Treatment Improvement (OTI) and the National Institute on Drug Abuse (NIDA). These two components of **ADAMHA** are developing a series of treatment guidelines that will cover perinatal women and substance-exposed infants. The guidelines will focus on treatment-methodologies and outreach method.

Office for Substance Abuse Prevention (OSAP)

(1) The National Clearinghouse for Alcohol and Drug Information (**NCADI**)

NCADI provides information in English and Spanish for the general public, health professionals, and others who seek knowledge about alcohol and other drug use during pregnancy. NCADI also serves as the **coordinating** point for public awareness activities such as National Alcohol- and Drug-Related Birth Defects Awareness Week. NCADI provides information about the prevention of Fetal Alcohol Syndrome and the names of state contact persons. The NCADI information number is: 1-800-729-6686.

(2) Community Partnership Program, Drug Use and Alcohol Abuse Prevention Demonstration Grants

These grants promote the development of long-range; comprehensive, multi-disciplinary community-wide drug use and alcohol abuse programs and prevention planning. These programs are coordinated through the formation and support of coalitions or partnerships of community-based public and private organizations. The goals are to achieve measurable and sustained reductions in drug and alcohol abuse among children and adolescents, reductions in drug related consequences, a reduction in drug related crime, and a reduction in workplace related drug abuse.

(3) National Perinatal Addiction Prevention and Technical Assistance Resource Center

OSAP recently established a national perinatal resource center to improve policy, practice and training on the prevention of maternal drug use and treatment of **drug-exposed** infants. The center will develop and disseminate information about promising prevention, early intervention, treatment, and rehabilitation practices; provide information and technical assistance; and help mobilize communities to address the problems of maternal drug and alcohol abuse. The center will also serve as a national repository for research on maternal abuse of cocaine, alcohol and other drugs.

(4) The Pregnant and Postpartum Women and Their Infants Demonstration Grant Program (**PPWI**)

This program, which was created as part of the Anti-Drug Abuse act-of 1988,. is administered in collaboration with **HRSA's** Bureau of Maternal and Child Health. The FY '91 appropriation is \$45.6 million. The PPWI service demonstration projects provide models or innovative approaches for prevention, education, and treatment located in community, **inpatient, outpatient**, and residential settings. The models address one or more of the following goals:

- promote the involvement and coordinated participation of multiple organizations in the delivery of comprehensive services for substance using pregnant and postpartum women and their infants;
- increase the availability and accessibility of prevention, early intervention, and treatment services;
- decrease the incidence and prevalence of drug and alcohol use among pregnant and postpartum women;
- improve the birth outcomes of women who used alcohol and other drugs during pregnancy; and
- reduce the severity of impairment among children born to substance using women.

(5) Research/Knowledge Transfer.

OSAP distributes information on the prevention and treatment of perinatal addiction gained from its demonstration programs in the field; NIDA research on the incidence and prevalence of drug abuse by pregnant women and the effects of drug abuse on the mother, fetus and newborn, as well as other **ADAMHA** clinical research through conferences, printed materials and technical assistance workshops. The conferences are often conducted in cooperation with other Government agencies and private organizations.

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

(1) Alcohol and Pregnancy Grant Program

In FY **1991** NIAAA supported **65 grants** totaling \$9.5 million on topics related to alcohol and pregnancy. This represents 'approximately **6.5 %** of the agency's total extramural research budget. NIAAA supports human and animal research in the following areas: assessment of offspring outcomes, determination of dose-response thresholds and critical periods of risk during fetal development, identification of factors mediating susceptibility and elucidation of the underlying mechanisms of alcohol-induced damage, development of prevention/intervention strategies, and development of methods for early identification of alcohol-abusing pregnant women.

The NIAAA supports 14 specialized alcohol research centers which provide long term support for interdisciplinary research, provide research training opportunities, and serve as national resources for dissemination of information about alcohol. An alcohol research center devoted to research on FAS has been funded since 1987. A multi-faceted research program seeks to elucidate mechanisms of damage, determine risk factors, and develop methods for identifying high-risk pregnancies.

(2) National Maternal and Infant Health Survey (NMIHS)

NIAAA was a co-sponsor of the 1988 NMIHS and 1990 Longitudinal Followup, which was designed to identify risk factors associated with infant mortality and morbidity. Twenty thousand mothers of live births, fetal deaths, infant deaths were interviewed. Of particular note is **that all infants for whom** Fetal Alcohol Syndrome **was listed** as -a complicating factor **or attribute** on the birth certificates are being investigated. In addition, the population of women who reported drinking more than 4 drinks a week was oversampled. The **followup** survey is examining the health and morbidity of the **10,000** live births from the NMIHS as well as a sample of the 1000 mothers who experienced an infant death in 1988. The data **from** these surveys are currently being analyzed by the **NIAAA's** Division of Biometry and Epidemiology.

(3) Health Professions Education Program

NIAAA supports this program in a joint effort with OSAP and NIDA. Clinical training grants were awarded to develop faculty skills in clinical teaching, practice and research on alcohol and drug abuse issues and to integrate alcohol and drug information into medical and nursing school curricula. NIAAA also co-funded with NIDA the development of a continuing education module on alcohol and drug abuse for use by **OB/GYN** clinicians.

Centers for Disease Control (CDC)

The National Birth Defect Monitoring System

FAS is one of the indicators monitored by this system. Reported incidence of FAS is based on identification at the time of discharge from specified hospitals.- This may result in underreporting of FAS, since it is difficult to diagnose FAS during the first two weeks of life. This underreporting may be compounded by the fact that some health professionals lack training in diagnosing FAS or are unwilling to report it.

Division of Reproductive Health

(1) Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS is a surveillance study of risk-taking behavior during pregnancy. This study is currently conducted at five state health departments.

(2) Household Survey on Indian Health among eight Native American tribes.

This survey is currently in the planning stages.

Division of Nutrition

(1) Behavior Risk Factors Systems (BFRS)

The BFRS is a questionnaire on drinking behavior that includes a question about whether the respondent is pregnant. It is not, however, a survey of pregnant women who drink.

(2) Pregnancy Nutrition Surveillance System

This survey includes questions about the frequency and quantity of alcohol consumption prior and during pregnancy and after delivery. It also includes questions on birthweight and neonatal mortality.

Division of Birth Defects and Developmental Disabilities

(1) Birth Defects and Genetic Diseases Branch

The Birth Defects Branch held a conference in April 1991 on FAS and other Congenital Alcohol Disorders (C-AD). The focus was on surveillance and evaluation, and intervention and prevention. The presentations addressed the needs of the mother as well as the child with FAS.

This branch is planning case control surveillance studies on FAS in several populations. It is also engaged in ongoing research to identify a biologic marker for FAS. Such a marker, which could be a gene or an enzyme, would help health professionals predict the incidence of FAS among drinking mothers with greater accuracy and consistency.

In September 1991, the Birth Defects Branch awarded \$175,000 under a cooperative agreement for a pilot program to develop and test improved surveillance methods for FAS within an existing community-based high-risk infant follow up program to Monroe County, New York.

The branch has also funded the Metro Atlanta Congenital Defects Project to conduct a study on **prevention-focused** surveillance for FAS. This project is a cooperative **agreement with Emory University** and the Georgia **Mental Health Institute..**

(2) Developmental Disabilities Branch

This branch will be working with the Alaska IHS and the state of Alaska to provide assistance for epidemiology studies. This effort is intended to improve surveillance strategies and intervention methods.

(3) The Disabilities Prevention Project.

This project has provided states with funds for the prevention of disabilities. Funds are equally divided between chronic disabilities, developmental disabilities and injury control since 1987. In FY '91 the funds devoted to developmental disabilities will be used to increase states' capacity to address FAS.

National Center for Health Statistics (NCHS)

National Maternal and Infant Health Survey (developed in conjunction with NIAAA). (See **NIAAA** above).

This survey was developed by NCHS and eleven other Federal agencies including NIAAA and first conducted in 1988. Three national samples of vital records and follow up questionnaires were collected throughout 1989. The maternal survey contained five questions related to alcohol consumption during pregnancy. The questionnaires for hospitals and prenatal care providers also contained elements relevant to alcohol use by mothers. The certificates of live birth and of fetal death adopted by 10 states asked about alcohol use during pregnancy, and the former identified fetal alcohol syndrome as an abnormal condition of the newborn.

Indian Health Service

IHS programs include both programs that address alcoholism in general and programs that specifically address FAS. In 1978, the IHS Office of Alcoholism was established. Over the next five years, 158 Native American alcoholism programs were transferred to **IHS** from NIAAA. In FY 1987, IHS funded 42 residential treatment centers, 23 halfway houses, 217 outpatient sites, and 163 prevention programs for alcoholism among Native Americans. In FY 1987, 19,811 individuals were treated in H-IS-funded alcoholism and substance abuse programs.

Public Law 100-713, Indian Health Care Amendments of 1988, directed the Indian Health Service to develop and implement a plan to reduce the rate of FAS among Native Americans served by or in behalf of the **IHS**, to 1 per 1,000 live births by 1994.

Funding for FAS Activities

In FY 1990, \$1.132 million of IHS funds were used to address FAS specifically. These funds were allocated in the following manner:

- (1) \$255,000 was distributed among the IHS Regional Areas for FAS Prevention activities;
- (2) \$250,000 was used to set up a national IHS FAS training team that will travel to the IHS areas to conduct regional workshops for IHS, tribal and community health workers;
- (3) \$527,000 was appropriated by Congress to establish an alcohol and substance abuse treatment center for pregnant women in Alaska; and
- (4) \$100,000 is designated for the University of Washington for FAS research.

In FY 1991, IHS allocated \$300,000 for an interagency agreement with the Centers for Disease Control to establish FAS surveillance systems in MS Aberdeen and Alaska Areas. It is anticipated that this surveillance effort will be expanded in future years.

Programs for Youth

Omnibus Anti-Drug Abuse Act of 1986 (P.L. 99-570).

This legislation funded treatment and prevention services for Native American youth. In FY 1989, \$18.7 million was available for these efforts. MS has used these funds to establish inpatient youth alcoholism and substance abuse treatment services in each of its 11 regional areas. It has also provided training through community education programs in every local Service Unit for 5000 physicians, nurses, alcoholism program workers, health educators, social workers, teachers, and law enforcement officers. This training includes FAS awareness.

FAS Research

Since 1983, Congress has funded FAS research and designated \$100,000 each year for The University of Washington's research efforts. The research has focused on psychological, intellectual and behavioral characteristics of FAS-affected children, the maternal psychological factors involved in FAS and vocational barriers for FAS adolescents. One of the recent products of this research is "A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Specific Reference to American Indians," which was published in 1988.

Training

An FAS workshop/training/conference team is planned for one of the IHS Area Offices. This team of professionals will provide technical assistance, consultation and training for IHS, tribal professionals and Native American communities. Through this effort, professional capacity and community awareness of FAS will be increased. Approximately \$250,000 has been set aside for this effort.

Area Office Efforts

In 1986, the Alaska area **IHS** and Alaska Native Health Board established a state-wide FAS program. The program has the following components: an FAS coordinator based in Anchorage, an Alaska-wide FAS services provider networking system, technical assistance for local FAS programs, training of MS health care professionals and other FAS workers, development of public education FAS prevention materials, community education, state-wide register of FAS children and women at risk of having an FAS child, coordination of FAS screening, provision of twice yearly diagnostic consultation clinics in Anchorage staffed by an expert dysmorphologist. In 1989, the Alaska Area Office received \$527,000 to set up a residential treatment facility for pregnant substance abusing Native American women.

In 1989, the Nashville Area Office improved its FAS prevention activities by designating an alcohol program aftercare specialist as the FAS technical advisor. Results have been increased awareness of FAS and several community and health care worker FAS education projects.

Other regional **IHS** offices have set up prevention programs, case management programs, training and technical assistance, and group homes for alcoholic pregnant women. Some have allocated funds to develop culturally specific FAS educational materials.

Computer Registry

A national **IHS** computerized registry software program for listing children with special needs is currently being developed and tested. This registry will include FAS **cases and other handicapping** conditions: The register will enhance-the tracking, case management and provision **of** services to children with special needs.

Infant Mortality Reduction

The **IHS** estimates that approximately **\$220,000,000** of its resources are used annually in **efforts** which relate to reduction of infant mortality. This includes prenatal care, **obstetrical** care, well-child care, and prevention and treatment of FAS and ARBD.

Aberdeen Area Pilot Project

IHS, in collaboration with other federal agencies, is developing a pilot project that will focus on the prevention, diagnosis, and provision of special education services for FAS-affected individuals in the Aberdeen regional area. This area includes portions of North Dakota, South Dakota and Nebraska. The project will provide grants to local organizations and attempt to redirect available IHS resources to fund these activities.

National Institutes of Health

National Institute of Child Health and Human Development (NICHD)

The Institute is funding a research project on the effects of prenatal alcohol exposure on infant growth.

Health Resources and Services Administration (HRSA)

Bureau of Maternal and Child Health

(1) Maternal and Child Health Block Grant (Title V)

These grants are awarded to State health departments using a formulas derived from the dollar amount each State received in FY'81. The purpose of these grants are:

- to assure access to quality maternal and child health services, **especially** for those with low income who are living in areas with limited availability of health services;
- to reduce infant mortality and the incidence **of** preventable disease and handicapping conditions among children;
- to provide rehabilitation services for blind and disabled individuals under age 16; and
- **to** provide assistance to children who are in need of special health care services.

Pregnant substance abusing women and children affected by **perinatal** drug exposure may qualify for services provided by the MCH Block Grant. Specific eligibility provisions are determined by individual states. Beginning in FY '91, regulations will require states to report the number of FAS and drug exposed children in **each state**. This will provide BMCH with national baseline **data**.²

(2) Special Projects of Regional and National Significance (SPRANS).

Each year, **10-15%** of the MCH Block Grant allocation is set aside to support SPRANS. SPRANS is a discretionary grant program that funds both **investigator-**initiated and program-directed research. Investigator-initiated research covers specific populations and general maternal and child health topics. Studies on specific populations includes research on prenatal care and provision of services after delivery. A listing of the SPRANS grants can be obtained from MCH by requesting the "Abstracts for Active Projects".

Administration for Children and Families

On April 15, 1991, **the** Secretary of **HHS** announced the creation of the Administration on Children and Families (ACF). This new operating division combines the programs and resources of the former Family Support Administration and Office of Human Development Services into one **agency**.³

Secretary's Coordinated Discretionary Program (CDP)

This program provides research and demonstration grants to states for programs served by **all** of **ACF's** Administrations. Some of these grants have addressed alcoholism.

² HRSA is planning to coordinate their reporting efforts with other agencies. The agency has recently issued an Request for Proposals from private organizations to assist with these coordinating efforts.

³ The Administration on Aging will continue to report directly to the Secretary, independent of the new operating division.

Office of Family Assistance

Aid to Families with Dependent Children (AFDC).

AFDC is a partnership program between federal and state governments that provides supplemental cash income to low-income families with dependent children who meet income eligibility criteria. States administer AFDC programs and set eligibility and payment standards within Federal guidelines. The Federal Government provides matching funds ranging from 50% - 80 %. Benefits vary considerably from state to state and according to the number of children in the family. Those who are eligible for AFDC are also eligible for Medicaid. If a child is receiving SSI benefits, he or she is not entitled to AFDC.

In FY 1989, about 3.8 million families (approx. 10.9 million persons) received AFDC each month; benefits averaged about \$381 per month per family.

Administration for Children, Youth and Families (ACYF)

Foster Care Program (Title IV-E).

Foster Care is an entitlement program that provides Federal matching funds to States to maintain **AFDC-eligible** children in foster care. Children receiving Title IV-E foster care payments are deemed eligible for Medicaid.

Comprehensive Child Development Program.

This is a demonstration to test the effectiveness of providing comprehensive services to at-risk children and their families from the birth of the child until the child enters elementary school. Alcohol and substance abuse prevention and treatment services are incorporated into most of the projects.

The Head Start Program. Head Start is a child development program which serves approximately 450,000 low income pre-school children. Head Start estimates that 20% of the children in the program have a parent or guardian with a substance abuse problem. They are currently planning training on these issues for their service providers **and are** field **testing an alcohol and** drug abuse prevention_ program in several of **their parent involvement** programs.

The Drug Abuse Prevention Program for Runaway and Homeless Youth.

This program provides alcohol and drug abuse prevention and treatment services for runaway and homeless youth. In FY 1991 it was funded at \$14.8 million.

National Center on Child Abuse and Neglect.

In July 1991, the Center announced the availability of \$18 million for approximately 20 three-year service demonstration projects to prevent the abuse or neglect of children whose parents are substance abusers. These projects will provide interdisciplinary coordinated services to address the needs of these children and their families. Grant awards were made in September, 1991.

Administration on Developmental Disabilities

University Affiliated Programs (UAPs).

ADD funds a number of universities for the purpose of providing interdisciplinary training for persons concerned with developmental disabilities, demonstrating exemplary services, providing technical assistance, and disseminating information. There are currently three **UAPs** that address FAS:

- (1) The South Dakota UAP, in collaboration with the State Division of Alcoholism and Drug Abuse, is coordinating a fetal awareness project that addresses detection and diagnosis. The South Dakota UAP is also working with the regional IHS on a training program for health care workers. (See Department of Education, OSERS, below);
- (2) The Tennessee UAP addresses early intervention, training of health professionals and comprehensive services to FAS children; and
- (3) **The Utah UAP** is concerned with FAS among Navajo Indians.

In addition, the Nebraska **UAP** houses the Ronald **Reagan Center for Birth Defects**. The Center's primary focus is providing information and resources on birth defects to high school students and the general public.

Administration for Native Americans

--In--F-Y **1987-89**, ~~through the Coordinated Discretionary~~ -Program;_ ANA- funded 14 -projects which focused on developing comprehensive prevention strategies to reduce-the incidence of alcohol and substance abuse among Native Americans.

Social Security Administration

Supplemental Security Income (SSI) Program.

This program provides cash benefits to needy elderly, blind, and disabled individuals and couples. Eligible persons may live in families, foster care or institutions. Over **300,000** disabled recipients are children and youth. The SSI program has been characterized by confusing eligibility criteria and a cumbersome determination process. There are two aspects to the eligibility problem for FAS applicants: many FAS children are developmentally disabled but have **IQs** that are too high to allow them to qualify for benefits, and FAS is not included in the medical listings used to determine eligibility for disability benefits.

Two recent changes in the SSI regulations will benefit this population. The first change is that the medical listing has been updated and now includes the multiple system/body damage typically associated with disorders such as FAS. The second change is the result of the Supreme Court's decision in Sullivan, Secretary of Health and Human Services v. Brian Zebley et.al. This ruling requires the Social Security Administration (SSA) to perform an individualized functional assessment for each affected child whose impairments do not meet or equal the severity of listed impairments. The Secretary of Health and Human Services is developing regulations to carry out this requirement.

Both changes will also help victims of FAS receive Medicaid benefits. In **thirty-nine** states, eligibility for SSI establishes eligibility for Medicaid. Six additional states have the same eligibility but require a separate Medicaid application. The remaining **thirteen** states have different eligibility criteria for the two programs.

Health Care Financing Administration

Medicaid

This entitlement program pays for the medical care of many low-income persons. Eligibility and covered services vary from state to state. States must provide Medicaid to all persons receiving Aid to Families with Dependent Children (AFDC), to most individuals and couples receiving Supplemental Security Income (**SSI**), and to certain low-income pregnant women and children. Medicaid is provided to pregnant women at **133%** of ~~the~~ poverty level. A recent program expansion now **requires States** to provide coverage to certain non-AFDC groups, 'such **as** 'pregnant women and postpartum **women** and their children under 5 years of age in families with incomes below **133%** of the federal poverty level. Medicaid also offers alcohol treatment services for eligible individuals.

HCFA has created demonstration projects to improve recruitment and retention of Medicaid providers. HCFA is also carrying out several demonstration projects to further improve access to care for this population.

Early Periodic Screening, Diagnosis and Treatment Services (EPSDT)

All states are required to provide EPSDT services to all Medicaid-eligible individuals under 21 **years** of age to “ascertain physical or mental defects” and to provide treatment to correct or ameliorate defects or chronic conditions found.

DEPARTMENT OF AGRICULTURE

Food and Nutrition Service

Special Supplemental Food Program for Women, Infants and Children (WIC)

In January 1990, the Secretary of Health and Human Services required state Medicaid programs to notify low-income pregnant women and mothers- that they or their children may be eligible for special high-nutrition food aid through the WIC program.

The WIC program distributes federal funds to states to provide specific supplemental foods and nutrition education to low-income mothers, infants, and children judged to be at nutritional risk. States administer WIC within broad federal requirements and designate local health or welfare agencies for local administration. In FY 1988, WIC provided supplemental foods to about 3.5 million women, infants, and children at a total federal cost of about \$1.8 billion. Most participants **are** certified for eligibility every six months. The WIC program is fully funded by the Federal government.

DEPARTMENT OF EDUCATION

Office of Special Rehabilitation Service (OSERS)

Early Intervention

The Office of Special Rehabilitation Service (OSERS) administers the early intervention component of the Education of the Handicapped Act Amendments of 1986 (Part H of P.L. **99-457**). Some FAS children will qualify for these services. Part H establishes a 5 year phase-in **program for planning interagency** coordination of **services** for ‘children **aged 0-2** years. For the first three years, states are given funding -for planning a statewide comprehensive and coordinated program of early intervention. In **the** fourth and fifth year, the states must provide case management services which include evaluation, assessment, and the development of Individual Family Service Plans. State participation is optional, and states that do participate may **determine** their own eligibility criteria. Part H identifies three areas that state programs should address: (1) developmental delays; (2) diagnosed physical or

mental conditions that have a high probability of resulting in developmental disabilities: and (3) at-risk populations.

Pre-school and school age education services may be available for an individual aged 3-21 with an identified education problem.

Discretionary Programs for Handicapped Children. This program funds grants for model initiatives and training. One of the areas addressed by this program is substance abuse.

Early Childhood Research Institute. OSERS' Early Education Program for Children with Disabilities has awarded a five-year research grant for an Early Childhood Research Institute on Substance Abuse. The institute is a five-year research and development effort to prepare, field test and disseminate interventions for children ages 0-5 who are developmentally delayed, at risk for developmental delay, or disabled because of maternal use of alcohol or drugs during pregnancy. The institute will be run by a **consortium** of three institutions in their respective cities: the University of Kansas (Kansas City), the University of Minnesota (Minneapolis/St. Paul) and the University of South Dakota UAP (**Vermillion**). The University of South Dakota UAP will conduct most of the research on programs for children prenatally exposed to alcohol.

Office of the Assistant Secretary, Drug Planning and Outreach Staff

The Department of Education's drug prevention programs are funded through the Drug Free Schools Program. The Department includes **alcohol** within the category of drugs because alcohol is an illegal substance for elementary and secondary school students.

State and Local Grants Program. The funds are divided between the State educational agency and the Office of the Governor. The State agency must allot a portion of their money to improve anti-drug abuse education, prevention, early intervention, and rehabilitation referral programs. The Governor must direct a portion of the funds to programs for high risk youth.

Programs for Indian Youths. This program is administered under a Memorandum of Understanding between the Departments of Education and Interior. Anti-alcohol and drug abuse education and prevention services are provided to Native **American children** attending elementary and **secondary education** schools on reservations which are operated by the **Bureau of Indian Affairs**.

⁴ FAS is specifically cited in this category.

Discretionary Grants Program. Some of the programs administered by the Department of Education under the Discretionary Grants Programs include:

(1) Grants for Institutions of Higher Education.

These grants are awarded to develop and implement drug education and prevention programs.

(2) School Personnel Training Grants Program.

These grants fund training for teachers and administrators in drug and alcohol education and prevention.

(3) Counseling Training Grants Program.

These grants fund training for participation in **drug** prevention,- counseling and referral services;

(4) Innovative Alcohol Abuse Education.

This program funds the development of materials for children in grades 5 through 8 that focus on the effects of alcoholism on families, especially on children of alcoholics.

DEPARTMENT OF THE INTERIOR

Bureau of Indian Affairs

FAS Awareness Activities. In conjunction with IHS, the **BIA's** Office of Indian Education sponsored an FAS Awareness Week in August 1991. The activities featured a "pink ribbon campaign" in which 15,000 BIA and **IHS** employees and school administrators throughout Indian country wore pink ribbons to alert the public to the risks of alcohol consumption during pregnancy. Each person wearing a ribbon also had a fact sheet on FAS to share with people who inquired about the disorder.

The Office of Indian Education is also sponsored a month of school-based activities on FAS and ARBD in the **fall of** 1991. The program featured audiovisual materials and a special curriculum on FAS to be used in **BIA** schools.

BTA-Funded Schools. The BIA-funded schools have no programs that are focused specifically on FAS or **ARBD**. All of the schools receive Chapter 1 funding and funding for special education programs. If a child with FAS or ARBD fits the profile for either of these programs, they can receive services through them.

The Drug-Free Schools and Communities Act includes a 1% set-aside for **BIA-funded** schools. These funds are used for general drug, alcohol and AIDS-prevention efforts, but do not focus on FAS or ARBD in particular. The programs sponsored by these funds include peer counseling and peer group development on drug and alcohol **issues.** (See ***Department of Education, Programs for Indian Youths***).

Early Childhood and Maternal Health Care Project. This pilot project is operating in cooperation with the Indian Health Service at six sites. It provides information on nutrition and promotes general health education (including the dangers of alcohol consumption). The project has two components, prenatal care and post-partum care of children up to age 5.

APPENDIX B

CONGRESSIONAL HEARINGS

SENATE

Select Committee on Indian Affairs

Field hearing in South Dakota on Child Abuse and Fetal Alcohol Syndrome. (5/90)

Committee on Labor and Human Resources

Subcommittee on Children, Families, Drugs and Alcoholism

“Breaking the Cycle: The Effects of Alcohol on Families.” (2/5/91)

Finance Committee

Subcommittee on Social Security and Family Policy

“Fetal Alcohol Syndrome.” (12/10/90)

HOUSE OF REPRESENTATIVES

Select Committee on Children Youth and Families

“Alcohol Abuse and Its Implications **for** Families.” (3/18/85)

“Born Hooked: Confronting the Impact of Prenatal Substance Abuse.” (4/27/89)

“Beyond the Stereotypes: Women, Addiction and Prenatal Substance Abuse.”
(4/19/90)

“Getting Straight: Overcoming Treatment Barriers for Addicted Women and their Children. ” (4/23/90)

ENDNOTES

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